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“It’s like a frog leaping about in your chest”: Illness and treatment perceptions in persistent atrial fibrillation.

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Statement of contribution

What is already known about this subject?

- Quality of life (QoL) is disproportionately low in people with persistent atrial fibrillation (psAF).
- The Common Sense Model (CSM) suggests illness perceptions and coping predict QoL in chronic illnesses.
- No previous studies have examined the idiosyncratic beliefs and coping behaviours of psAF patients.

What does this study add?

- In psAF emotional representations may be an outcome of illness perceptions and not processed in parallel.
- Avoidance/all-or-nothing behaviours continued despite symptomatic relief and may lead to sustained low QoL.
- Treatment beliefs related to AF-procedure were highly related to illness perceptions and may inform QoL.

Objectives: Persistent atrial fibrillation (AF) is an abnormal heart rhythm associated with low quality of life (QoL) and significant health-related costs. The purpose of the study was to examine patients' illness and treatment beliefs and ways of coping with AF symptoms, to provide insight into promoting better QoL and treatment-specific management.

Design: Beliefs were explored across three procedural treatment-groups using a qualitative cross-sectional design.

Methods: 30 semi-structured interviews were carried out with patients undertaking cardioversion ($n=10$), catheter ablation ($n=11$) and atrioventricular node ablation ($n=9$). Interviews were transcribed and analysed using inductive thematic analysis with elements of grounded theory.

Results: An overarching theme of a vicious cycle was evident, which related to perceived lack of knowledge and understanding of AF, attempts to control symptoms and negative emotional reactions to failed control attempts. This vicious cycle related to three subordinate themes (i) Unpredictability and uncertainty of AF and symptoms; (ii) Coping with symptoms through (a) avoidance (b) all-or-nothing- (c) slowing down behaviours; and (iii) Concerns and expectations about treatment.

Conclusions: Patients outlined a need to gain control of unpredictable symptoms by monitoring and varying activity levels. These behaviours were often appraised as ineffective at controlling symptoms, leading to heightened uncertainty and increased activity-avoidance. Treatment concerns escalated with increasing number and invasiveness of procedures. Improving AF patients' perceived understanding of their illness and treatment and promoting more effective symptom-management strategies may alleviate psychological distress and improve QoL. Themes elaborated on the Common-Sense-Model whereby patients' beliefs about illness and treatment interact with coping behaviours.

Introduction

Atrial fibrillation (AF) is a rapid, chaotic and irregular heart rhythm affecting the upper chambers of the heart. It is a major cause of stroke, heart failure and cardiovascular comorbidity and is independently associated with a two-fold increased risk of all-cause mortality in women and a 1.5-fold increase in men (Kirchhof et al., 2016). AF affects 5% of the population aged over 65, is implicated in 20-30% of strokes and contributes to 1% of National Health Service (NHS) expenditure in the UK, 50% of which is due to hospitalisation (Kirchhof et al., 2016; Stewart, Murphy, Walker, McGuire & McMurray, 2004). Paroxysmal AF is defined by episodes of arrhythmia which terminate spontaneously within seven days of onset, whereas persistent AF (psAF) is diagnosed when arrhythmias are sustained for more than seven days (Kirchhof et al., 2016). PsAF is deemed 'long-standing' when it has been continuous for more than 12 months and 'permanent' when an agreement is made between the clinician and patient to stop further attempts to restore normal heart rhythm (Kirchhof et al., 2016). AF is commonly associated with structural heart disease and comorbidities including hypertension, heart failure, obesity, sleep apnoea and diabetes. Patients with AF typically have both symptomatic and asymptomatic arrhythmia episodes and when symptomatic, commonly experience fatigue, palpitations, shortness of breath and dizziness (January et al., 2014; Pyrstowsky, Padanilam & Fogel, 2015).

Evidence suggests that patients with psAF have poorer quality of life (QoL), higher risk of stroke and mortality, and higher levels of depression than other types of AF (Bulková et al., 2014; Steinberg et al., 2014, von Eisenhart Rothe et al., 2014). QoL is also lower in psAF than other cardiovascular populations, including post-myocardial infarction patients and those with significant coronary artery disease who are often older and may require percutaneous or surgical intervention on symptomatic and prognostic grounds (Dorian et al., 2000).

It is not clear why psAF patients have worse QoL than patients with significant coronary artery disease who have a higher risk of mortality (Dorian et al., 2000). Neither is it clear why clinical improvements such as restoration of normal sinus-rhythm post-treatment, do not always translate to improvements in QoL (Erdogan et al., 2003). The Common-Sense Model (CSM; Leventhal, Brissette & Leventhal., 2003), supported by a large body of research, suggests patients' beliefs about their illness and treatment (illness and treatment representations) and methods of coping with symptoms, predicts QoL and adjustment across chronic illness groups such as lower back pain, asthma and cardiovascular disease (Foster et al., 2008; Hagger & Orbell, 2003; Juergens, Seekatz, Moosdorf, Petrie & Rief, 2010; Kaptein, Klok, Moss-Morris & Brand, 2010). Patients' awareness of their symptoms leads to the development of key illness representations, consisting of identity (symptoms), cause (beliefs of the antecedent factors of illness), timeline (acute, chronic, or cyclical nature of illness), consequences (effects on social, psychological and physical functioning), and control/cure (treatment or personal control over illness) (Leventhal et al., 2003). In addition, illness coherence, which describes how well individuals feel they understand their illness, can affect patients' motivation to undertake appropriate coping actions (Cameron & Moss-Morris, 2010). Illness coherence beliefs may relate to understanding the causes, symptoms and management of illness. Emotional responses also interact with illness representations and can both activate and be activated by illness representations (Cameron & Moss-Morris, 2010). The CSM proposes that cognitive and emotional representations guide coping. Appraisal of the efficacy of coping behaviours are then fed back, altering representations and chosen coping behaviours. While clinical evidence of disease severity is important, focus should also be on patient-reported outcomes such as functional ability and impact on everyday life. Examining illness-specific experiences and illness perceptions may elicit beliefs which are pertinent to a particular population and is a key stage to developing

individualised interventions (French & Weinman, 2008). The CSM provides a theoretical model to examine how patients perceive and experience AF and how they interpret and respond to symptoms which allows researchers to more appropriately target ways to manage patients.

The CSM is somewhat supported in three previous studies which address general AF patients using generic measures of illness representations. Lane, Langman, Lip and Nouwen (2009) examined lone (idiopathic) AF patients and found patients attributing more symptoms to AF (illness identity) had greater physical health deterioration over 12 months. Greater concerns about medications and higher consequences scores were associated with better physical and mental health. The latter finding was explained by increased information seeking behaviours, however coping behaviours were not measured. Previous studies suggest that lone AF contributes to only between 2 and 31% of the AF population, (Chugh et al., 2001) so findings from Lane et al. (2009) were not representative of general AF experience. Steed, Newman and Hardman (1999) addressed long-standing and paroxysmal AF patients and found that the components of identity and consequences were the strongest predictors of adjustment. However, there was little association between coping and illness representations, as suggested by the CSM and coping did not predict adjustment. The authors highlight that the lack of support for the role of coping in predicting adjustment could be a result of using a generic measure of coping (COPE Inventory; Carver, Scheier & Weintraub, 1989), which does not sufficiently account for AF-specific coping behaviours. However, a study by McCabe and Barnason (2012) which used generic measures of coping found that coping behaviours could predict psychological distress. In the original CSM, (Leventhal et al., 2003) coping is conceptualised as specific behaviours rather than generic coping strategies. To date, no studies have defined or investigated the specific coping behaviours people with AF use to adapt to and manage their condition. An important aspect of the CSM which is seldom

studied is the more dynamic aspect of the model including how appraisal of coping efforts may affect both cognitive and emotional representations. Little is known about the idiosyncratic beliefs and experiences that may be unique to psAF, which may guide coping behaviours and ultimately affect QoL.

Patients' beliefs about treatment (treatment beliefs) may also affect coping behaviours. Horne (2002) suggests treatment beliefs consist of beliefs about the necessity of treatment and concerns about the negative effects of treatment. He proposed that cognitive and emotional treatment representations are processed in parallel and interact with cognitive and emotional illness representations. For instance, illness beliefs about the severity of illness may influence treatment necessity and in turn, treatment concerns may affect illness control/cure beliefs. To date, most research on treatment beliefs relates to beliefs about medication rather than procedural treatments and as far as we are aware, no studies have addressed AF-specific treatment beliefs. Examining AF patients' treatment beliefs and the potential behavioural and emotional consequences of these cognitions, may help researchers to target modifiable factors to better prepare patients prior to and following procedures to promote better QoL post-treatment.

There are three commonly used treatment-procedures in psAF; direct current (DC) cardioversion, catheter ablation and atrioventricular (AV) node ablation with pacemaker. Cardioversion involves delivery of a synchronized electrical shock to the outside of the chest with the aim of restoring normal sinus rhythm (Fuster et al., 2006). The relapse rate is high with approximately 25% of patients in normal sinus rhythm at the end of one year (Lundstrom & Ryder, 1988). Patients resistant to cardioversion may undergo catheter ablation. This uses radiofrequency energy to scar areas of the heart which provoke AF, particularly around the pulmonary vein (January et al., 2014). Although this approach has been shown to be effective, further ablations may be required for 20-40% of patients due to

AF recurrence (Kobza et al., 2004). When these techniques are not successful, AV node ablation may be used, which involves the use of radiofrequency energy to block electrical conduction between the atria and ventricles and insertion of a permanent pacemaker to control heart rate (Fuster et al., 2006). Patients who have AV node ablation show consistent improvement in symptom reports, QoL and healthcare use (Wood, Brown-Mahoney, Kay & Ellenbogen, 2000). In addition to procedural treatments, AF patients are likely to undertake anticoagulant medication, such as warfarin, to reduce stroke risk and antiarrhythmic drugs which may increase the likelihood of restoration of sinus rhythm after procedures (Fuster et al., 2006).

Patients may undergo more than one of the procedures as outlined above during the course of their illness, each with differing levels of invasiveness and associated discomfort. The contrasting nature of these procedures may also explain why there may be differences in QoL based on psAF procedure, for instance cardioversion procedures represent temporary AF alleviation in comparison to AV node ablation which provides a more long-term cure, although as far as we are aware no previous studies have directly compared patients' QoL following these procedures. Exploring patients' views of these procedures, as well their beliefs about AF, ways of coping with AF symptoms and how AF may have impacted their lives, may help to examine these potential differences and factors associated with QoL.

The aim of this study was to use inductive qualitative methods to (1) explore people's experiences of psAF and the three commonly used treatment procedures (2) how these experiences relate to illness and treatment representations and (3) how these representations may guide coping strategies and appraisal of these strategies, with the view to gaining insight into how these may impact QoL.

Methods

Participants

Ethical approval was granted through the Health Research Authority NHS ethics (Ref: 14/NE/0096). Purposive sampling was used to recruit patients with diverse demographics and to capture a range of potentially different experiences. Thirty patients were recruited before data saturation was reached i.e. sufficient data was attained to represent patients' experiences and no new themes emerged from the data (Glaser & Strauss, 2009). Patients attending cardiology clinics ($n=24$) were approached by a member of the direct-care team. If patients were interested in finding out about the study they were directed to the researchers who gave patients information sheets and consent forms to read. The sampling frame used to guide purposive sampling included a clinic list of all arrhythmia patients attending pre-assessment appointments prior to procedures (catheter ablation and cardioversion) and a procedural list for patients undergoing AV node ablation. In this way, characteristics being sampled included pre/post procedural status, procedure type, gender and type of AF. Patients were also recruited online from the Atrial Fibrillation Association (AFA) webpage ($n=6$) which enabled the research to obtain a wider UK perspective of AF patients. All participants were given the option to ask questions about the study before being screened for eligibility. Informed consent was given by all participants who agreed to take part. Inclusion criteria can be found in Table 1.

Interviews

Telephone interviews consisted of semi-structured and open ended questions (Table 2). Interviews were audio-recorded and conducted in an interview room at the research department by two researchers who had previous interviewing experience. Field notes were taken during the interviews, which lasted between 15 and 43 minutes. Care was taken to avoid leading questions and minimal probing was used except for clarification or elaboration.

Data Analysis

Interviews were transcribed verbatim and checked to ensure accuracy. Inductive thematic analysis with elements of grounded theory was used to ensure themes were strongly linked to the data and allowed a coherent story of patient experience to be developed, rather than just using a descriptive approach. Analysis was guided by methods outlined by Braun and Clarke (2006). Line by line coding was done manually for the first 10 transcripts and initial codes closely reflecting raw data were written in the transcript margins. Codes for as many potential themes as possible were generated, including relevant surrounding detail to ensure context was not lost (Glaser & Strauss, 2009). For instance, the context in which patients reported experiencing emotions in response to their illness was important as this could relate to either immediate symptoms or anticipation of symptoms. Codes were sorted into broader initial themes. Elements of grounded theory were incorporated into the analysis by using the constant comparative method in which data was simultaneously collected and analysed. This technique involves systematic comparison between transcripts and ongoing interpretation of data to refine themes, ensuring that all themes are grounded in the data. Any discrepancies in coding between three of the researchers were discussed and agreed. Final themes and sub-themes were revisited, re-read and refined to ensure an accurate depiction of patient experience was captured (Glaser & Strauss, 2009). Finally, representative examples of participants' scripts were selected to support the analytic narrative of each theme.

Results

Sample demographics are summarized in Table 3. The sample was relatively evenly split between those pre- and post-treatment and across treatment types. One third were women and the mean age was 61.6 ($SD= 11.98$). Just over half the sample had tertiary level education and two thirds were married or cohabitating. There were few differences between

AFA and clinic patients except that the majority of AFA patients (5 out of 6) were undergoing cardioversion whereas procedure-type was more evenly split in clinic patients.

An overarching dominant theme emerged which we have labelled ‘a vicious cycle’. This theme is initially presented separately and then elaborated under three further interlinked key themes which exemplified the experience of people with psAF: (i) Unpredictability and uncertainty of AF and symptoms (ii) Coping with symptoms, including 3 sub-themes of (a) avoidance of activity, (b) all-or-nothing behaviours, (c) slowing down, and (iii) Concerns and expectations about treatment. Additional quotations illustrating each theme can be found in Table 4.

A vicious cycle

A strong theme related to descriptions of a vicious cycle of perceived lack of knowledge and understanding of AF, attempts to control AF and emotional reactions to failed attempts at control. This vicious cycle is represented graphically in Figure 1. Some patients described a perceived lack of understanding of psAF including the triggers of symptoms, ways to respond to symptoms and adverse consequences of symptoms, such as whether palpitations could lead to a stroke or heart attack. Poor perceived knowledge of AF was often linked to beliefs that AF was unpredictable and could occur at any time which in turn linked to specific coping behaviours such as avoidance. When avoiding activity or slowing down failed to control symptoms, patients often spoke about frustration and/or distress. Distress in turn was seen by some to trigger AF or to make them more acutely aware of their AF. Failed attempts to control symptoms also seemed to fuel beliefs that AF was unpredictable and uncontrollable.

An example of the vicious cycle is provided by participant 19.

“I don’t understand it...Without any warning your heart races really fast...It’s a frightening experience. The first time it [AF symptoms] happened, I thought I was going to die... Nothing works. Every time it happens I don’t know what to do because they [HCPs] haven’t told me whether to take extra medication or anything so I have no control. I just try to take it easy but it doesn’t work. All I know is that I’m really frightened.” (P19)

Patients with better perceived knowledge, particularly about symptoms such as heart palpitations did not seem to experience this vicious cycle and reported greater feelings of control:

“The heartbeat disturbs people the most. For me, I can calm myself down. I know my heartbeat’s going awry and I don’t panic as much now. I know I’m not going to have a heart attack or stroke because I’m on warfarin.” (P10)

One patient recognised elements of the vicious cycle and mentioned the importance of curbing anxiety in response to experiencing unpredictable symptoms. Having better perceived knowledge of AF seemed to be associated with better coping and emotional regulation which mitigated the vicious cycle.

“I’ve learnt to break the cycle between symptoms coming along and that worry cycle which just escalates how I’m feeling.” (P2)

Unpredictability and uncertainty of AF and symptoms

For highly symptomatic patients heart-related symptoms such as palpitations were a major concern. Vivid metaphors were used to describe palpitations such as *“a frog leaping about in your chest”* or *“a jumping bean.”* Patients were cognisant of the importance of the heart in bodily function and felt anxious that palpitations could signal a heart attack or risk of mortality.

“When you feel your heart beating fast and irregularly like that, there’s a thought process. The heart’s an extremely important organ and if it stops working, things are going to get bad very quickly.” (P15)

On initial experience of AF, patients were likely to seek hospitalisation due to concerning palpitations. Uncertainty about palpitations and continued use of emergency services could also be prevalent over time:

“Normally I’d end up calling the ambulance because my heart was just racing and wouldn’t stop...16 times I had to call an ambulance last year.” (P17)

Palpitations also concerned non-specialised Health Care Practitioners (HCPs) who detected arrhythmia during routine checks and advised immediate hospitalisation.

“It scared the nurse more than it scared me. She would stick me on a bed, do an ECG and wouldn’t let me budge until the ambulance arrived.” (P27)

Patients most commonly experienced breathlessness, fatigue and palpitations. Many felt symptoms were debilitating, unpredictable, and could occur at any time, leading to constant anticipation of symptoms and disruption to everyday life:

“It was just so unpredictable. I couldn’t make arrangements to go out anywhere in case it started.” (P9)

“It’s frustrating, really frustrating, because you never know when it’s going to happen.” (P2)

In relation to the overarching vicious cycle theme, many patients had low perceived knowledge of their AF, therefore found symptoms unpredictable and distressing, and attempted to control symptoms by engaging in a variety of coping strategies (Figure 1).

“When the doctor said I had AF I was shocked and gutted because I do all the healthy things the government advise...I go swimming, I go for walks every day. Where’s it going from here? I don’t have sugar in my tea. I don’t eat cakes or biscuits. I’ve been resting because then I’ll get better.” (P1)

Coping with symptoms

Patients described three predominant behavioural coping strategies in response to their symptoms: avoidance of activity, all-or-nothing behaviours and slowing down. Patients avoided activities such as exercise which they believed might trigger AF. As a consequence, patients interacted less with others and engaged less in enjoyable activities.

“Since I’ve had AF, I’ve gone from being a very active person to having a very sedentary life. I have to be careful what I do as I get tired very quickly and I’m not sure if I should be doing something or not.” (P29)

“If you start to do exercise then it’s actually going to get worse so you just don’t.” (P10)

Some patients engaged in all-or-nothing behaviours and would oscillate between over-activity when symptom free and under-activity when experiencing symptoms.

“Some moments I think great, I’m getting good and normal and then I’ll do something and over-do it and I’ll feel very tired again.” (P29)

These patients were able to gain initial control over symptoms but at the cost of frustration and worsening symptoms later. Patients who reported this cycle, viewed their illness as an obstacle to overcome, described themselves as resilient individuals who didn’t “*make a fuss*” (P23) and attempted to persist with pre-AF-diagnosis activities. Juxtaposed engagement in over-activity and under-activity could be distressing and make patients feel fraudulent:

“At one time I’d be pulling roofs off, building things and then two days later I couldn’t get out of a deck chair which makes it look like you’re a con-artist.” (P6)

Carrying on with the same pace of life led some patients to feel worse, however other patients who continued engaging in activities but at a slower pace, did not seem to experience the distressing effects of AF.

“I continue to live life fairly normally. I’m still working three days a week. I’m more cautious, like at the gym. I don’t go outside my comfort zone but it doesn’t place huge restrictions, I’ve just slowed down.” (P3)

Slowing down also seemed to be related to better adjustment after procedures.

“I’ve been taking it easy and I’ve been going to the swimming pool. I’m not gung ho but it’s early days yet and I’m pretty pleased with the treatment.” (P15)

For patients who slowed down, a diagnosis of AF provided a welcome explanation and better understanding of why they were having worrying symptoms and seemed to be associated with alleviated concern and uncertainty. A label of AF allowed patients to achieve some control over symptoms and despite concerns that procedures would not provide long-term symptom relief, patients continued to engage in steady activity.

“It wasn’t so much the diagnosis...at least I know now why I lost my energy levels.” (P28)

In relation to the overarching vicious cycle theme, patients used all-or-nothing behaviours, avoidance or slowing down to try to gain control of unpredictable symptoms. Patients who appraised their coping efforts as ineffective reported experiencing emotional distress. Some patients continued to search for AF triggers to try to control symptoms, fuelling increased avoidance of activities and escalating distress.

“Nobody really knows what triggers it so I tried all these different things, leaving off tea, but nothing seems to make much difference.” (P20)

“The fact that I don’t know what’s triggered it...why I’ve got it... It could come back at any time. I don’t know if I’m doing anything wrong.” (P13)

Avoidance could persist even after successful treatment and when patients no longer experienced symptoms, as patients were fearful of triggering recurrence of symptoms. This resulted in long-standing disengagement from enjoyable activities and exercise, and was particularly evident in catheter ablation patients who doubted procedural efficacy due to previous failed cardioversions and advice from HCPs about the likelihood of having to have further procedures:

“I go more slowly. I don’t want to risk putting myself back into AF. It could be all too easy.” (P3)

Advice from HCPs could guide both patients’ avoidance and engagement in activities:

“I have been trying to put my washing out, but the cardiac matron said I shouldn’t really be doing that.” (P29)

“It’s getting into a situation where you believe them [HCPs]. Eventually you start and you play badminton and lift weights and it doesn’t have any effect.” (P27)

Many AF patients reported feeling uncertain of how to cope and worse-off than other cardiovascular patient-groups. Some patients highlighted the lack of rehabilitative support groups for AF patients and argued that AF symptoms had a more profound and long-lasting effect on QoL than acute cardiovascular events:

“I’ve had friends who have had a heart attack and they’re living, going to rehab classes, cycling. They go walking and travel. For me, I can’t. It’s so frustrating.” (P29)

Concerns and expectations about treatment

Differences in treatment concerns were observed between procedural-groups and were related to patients’ experiences of previous failed procedures. Patients had decreasing faith that procedures would restore sinus rhythm, as treatment-procedures escalated, which resulted in concerns about the efficacy of AV node ablation, despite 100% guaranteed success. Cardioversion patients had few concerns about the cardioversion itself and were more concerned about the anticoagulant drug, warfarin. One patient referred to warfarin as *“rat poison”* (P5) while others were concerned about the side effects.

“When you first go on warfarin you think flipping hell, I better not cut myself or brush my gums too hard.” (P25)

Some found it difficult to distinguish between the side effects of medication and the symptoms of AF.

“It’s hard to know where one starts and the other stops. I don’t know how much of it is the AF and how much of it is the warfarin and statins.” (P7)

As a first-line procedural-treatment, cardioversion patients were hopeful that cardioversion would restore normal sinus rhythm, had few concerns about cardioversion and felt it was necessary and desirable to improve QoL, but was not *“life-saving.”* (P28)

“After the cardioversion, I’m expecting to be a spring chicken again. At my age that’s a bit hopeful but nevertheless that’s what I’m expecting.” (P28)

While cardioversion patients were experiencing AF procedural treatments for the first time, catheter ablation patients were likely to have had at least one previous failed cardioversion and viewed the ablation as “*plan B*” (P3). Catheter ablation patients highlighted concerns about increased intrusiveness and extended hospital-stay in comparison to previous cardioversions. Efficacy was a key concern:

“My big sort of fear I suppose is that I shall go through all the aggravation of it and take the risks and be no better off at the end.” (P3)

Advice from clinicians that repeat procedures might be necessary increased concerns that catheter ablation would not alleviate symptoms and restore sinus rhythm. This led some patients to feel frustrated and to be acutely aware of potential treatment failure both pre-and post-treatment. Both catheter ablation and cardioversion patients felt that after their procedures they could not comment on whether their procedures were successful. They reported that this was because HCPs had expressed that they were uncertain as to how long the treatment would last. Some patients had been told by HCPs that treatment might last a month or a year. Some patients reported low expectations of the efficacy of catheter ablation to avoid repeated disappointments.

“It’s a bloody nuisance because it’s obvious that they don’t expect it to work the first time.” (P6).

Having had previous failed treatments, catheter ablation patients were more likely to perceive the ablation as necessary. Many catheter ablation patients were also more symptomatic than cardioversion patients and felt the procedure was highly necessary even if it provided only minor symptomatic relief.

“I’ve got to do something. I can’t feel like this all of the time. It takes too much out of your life.” (P6)

Similarly, AV node ablation patients were usually highly symptomatic and therefore felt their procedure was highly necessary, with some suggesting it to be life-saving. Patients felt *“there was no choice but to take the risks”* (P26) of the procedure and viewed it as a process of *“escalation and elimination”* (P21) and last resort.

“It was very necessary as otherwise I don’t think I’d be around for too much longer.” (P22)

Having had multiple failed cardioversions and catheter ablations, AV node ablation patients were concerned that symptoms would not be alleviated despite guaranteed control of heart rate with the insertion of a pacemaker. Following the procedure, patients were reluctant to report alleviation of symptoms before confirmation of procedural-success with consultants at follow-up appointments.

“I don’t have huge expectations simply to avoid disappointing myself too much. Over the years I’ve had, at different times, such high expectations and these have proved not to be born out in practice.” (P21)

“I was expecting to feel 100% better than I do now. I’m waiting to see the consultant to get them to check if the pacemaker has held.” (P29)

A small proportion of post-AV node ablation patients reported disappointment at remaining symptoms, which were likely to be associated with other comorbidities, but led to the perception of failed treatment.

“I’ve got so many things going wrong that I don’t know if AF is still affecting me.” (P30)

Misattributing other symptoms to AF led to reported distress at the perceived failure of treatment. AV-node ablation patients were also concerned by reliance on an unnatural pacemaker which patients believed could malfunction.

“It’s a strange thought to think that you’re living and being worked on a machine.” (P29)

Generally, patients undergoing all types of procedures seemed to have less faith that their procedural-treatments could control AF symptoms, and had more faith in their own behaviours. This fits in with the vicious cycle theme which emphasises that patients respond to unpredictable symptoms using specific coping behaviours. The quote below illustrates the importance attributed to personal control behaviours.

“The doctor thought catheter ablation would be the more likely way of getting rid of AF for good, but I wanted to see first, with the idea being that if I can control my stress and lifestyle and the amount of beer I drink, it’ll go away, you know? Or it won’t come back.” (P5)

Discussion

The findings from this qualitative study illustrate the dynamic nature of symptomatic experience in psAF patients and how these influence AF beliefs, coping, appraisal and emotional responses over time. Many psAF patients felt caught in a vicious cycle whereby people who felt they had poor knowledge and understanding of psAF (low illness coherence) reported experiencing unpredictable symptoms. Behavioural attempts to control symptoms through regulating activity, particularly all-or-nothing and avoidance behaviours, led to unfavourable evaluation of control and emotional distress, suggesting a possible pathway to poor QoL. Although this vicious cycle was seen in many AF patients, some patients said they were able to steadily continue with everyday activities and did not mention avoiding activity or situations. Some of these patients suggested that greater perceived understanding of AF

and AF symptoms increased feelings of control.

PsAF patients' experiences were largely in line with the CSM (Leventhal et al., 2003). AF symptoms led to the activation of illness beliefs and coping behaviours. When patients appraised coping as ineffective they reported a range of negative emotional responses. In this way, the data slightly diverge from the proposed parallel processing of cognitive and emotional representations outlined in the CSM (Leventhal et al., 2003) as the emotional representations were more an outcome of the concrete illness representations and associated coping. In order to examine this in more depth, further longitudinal quantitative research is required.

In addition to cognitive and emotional representations, patients' experiences of feeling fraudulent when symptoms affected them differently on a day-to-day basis, points to a possible social representation of illness. Perceived lack of understanding from others may contribute to invalidating how patients feel about their illness, causing further distress. Possible social representations of illness should be examined in future quantitative research and may inform future interventions that target these issues, either by addressing psAF patients' perceptions about others' responses to their illness, or providing psycho-education to family members about the nature of psAF.

The data highlighted dimensions of the illness and treatment representations which may be most important to consider in the context of AF. Illness coherence is associated with psychological distress in AF (McCabe & Barnason, 2012). Previous research has suggested that AF patients have low perceived knowledge of their AF and pharmacological treatments such as warfarin (Koponen et al., 2007). The current study suggests that psAF patients who perceived themselves to have a good understanding of their illness may be more likely to cope better. PsAF patients who reported low coherence about their AF related this to unpredictable symptoms, treatment and management of AF symptoms. PsAF patients also

reported feeling unsupported by HCPs in comparison to patients with other cardiovascular illness who received rehabilitative support, which may provide some indication as to why AF patients experience such low QoL in comparison to other cardiovascular patients (Dorian et al., 2000). Rehabilitative support, particularly around maintaining heart health and engaging in regular exercise may be beneficial to psAF patients. Interventions are also needed to train HCPs to help improve patients' understanding of their treatment to prepare them for procedural treatments, with the aim of improving outcomes post-treatment, although to our knowledge, there is little research into procedural-treatment coherence in general and none in AF.

In addition to illness coherence, patients in the current study who attributed a wide range of symptoms to their AF seemed to experience more distress. This is consistent with previous AF CSM research which found high illness identity was associated with poorer QoL (Lane et al., 2009; Steed et al., 1999). In our study misattribution of symptoms as life-threatening could lead to persistent hospitalisation. Hospitalisation could also be fuelled by advice from non-specialised HCPs who detected AF during routine check-ups and immediately admitted patients to Accident and Emergency. These findings indicate the necessity for educational-interventions to help patients and non-specialist HCPs recognise and understand potential consequences of psAF symptoms, particularly palpitations and may help reduce patient distress and acute hospitalisation.

The current study also found that procedure-specific concerns appeared to contribute to distress, incorporating the broader CSM framework proposed by Horne (2002). Patients used the necessity-concerns framework to weigh up their expectations and beliefs about treatment, but the current study highlighted a number of sub-factors specific to AF patients, which contributed to this framework; concerns increased with invasiveness of treatment. Concerns were higher in AV node ablation patients who required a pacemaker, than

cardioversion or catheter ablation patients. In addition, the more treatment procedures patients underwent, the less faith they had that procedures would alleviate symptoms and restore normal sinus rhythm. Cardioversion patients who had not previously undertaken any procedural-treatment for AF seemed to have less efficacy concerns than catheter ablation patients who may have had multiple failed cardioversions and ablations. AV node ablation patients who were likely to have had the most procedures had the highest efficacy concerns. To a lesser extent, necessity also played a role in how patients viewed procedures. Patients who were more symptomatic and whose previous treatments had not worked were more likely to view procedures as necessary. AV node ablation patients viewed their procedure as most necessary in comparison to patients undergoing cardioversion and catheter ablation. The way in which clinicians provide information on temporary alleviation procedures such as cardioversion and to some extent, catheter ablation, should differ in comparison to more long-term cures of symptoms in psAF, such as AV node ablation. Increasing perceived knowledge of procedures and providing better certainty, even to highlight the limitations of a single ablation procedure and the likelihood that AF cure may only be obtained over repeated procedures, may be beneficial to alleviate distress and avoidance behaviours

Although a previous study has suggested coping in AF does not play a mediating role between illness representations and outcome (Steed et al., 1999), the current study suggested a possible pathway between illness cognitions, coping behaviours and subsequent distress. Avoidance is a predominant coping response in tachycardia patients (Ekblad et al., 2013; Wood, Wiener, & Kayser-Jones, 2007). The current study found that psAF patients increased control-attempts by avoiding a wider range of activities when they felt unable to control symptoms, leading to worsened feelings of illness burden. Avoidance due to fears of recurrence continued post-treatment, regardless of whether normal sinus rhythm was restored, providing insight into sustained low QoL post-procedure. Patients' concerns of engaging in

physical activity may be unfounded as no evidence suggests that exercise predicts recurrence, and paradoxically it has been associated with fewer AF episodes (Pathak et al., 2015). In turn, avoidance behaviours have been associated with mortality in heart-failure patients (Murberg, Furze & Bru, 2004). HCPs played a role in both encouraging engagement and avoidance of activity indicating the importance of reviewing advice-giving practices and behavioural management.

All-or-nothing behaviours, not previously reported in AF, may also be unhelpful and have been shown to predict ongoing experience of symptoms following an acute infection or injury (Moss-Morris, Spence & Hou, 2011; Spence & Moss-Morris, 2007) and predict onset of chronicity illnesses such as irritable bowel syndrome (IBS) and post-concussion syndrome (Hou et al., 2012; Spence & Moss-Morris, 2007; Moss-Morris, 2005). In this study, all-or-nothing behaviours appeared to be related to close monitoring of symptoms and possible misattribution of symptoms to AF rather than to erratic patterns of behaviour.

Finally, slowing down but not avoiding activities altogether when symptoms are more severe may serve protective functions and enable patients to adapt to their illness (Spence & Moss-Morris, 2007). Patients in the current study who steadily continued with their everyday lives, even if cutting back a bit where they felt necessary, were less likely to report distress. Future quantitative research is needed to measure these three behaviours to clarify whether they are in fact related to distress in the ways discussed.

The study had a number of limitations. We attempted to recruit a diverse group of patients from cardiology out-patient clinics and the AFA webpage to represent a range of views. Despite this, patient care may differ between hospitals leading to different reported illness and treatment experiences. AFA participants may also be more motivated to disclose their experiences, as users of an online information and support group. Nevertheless, the

sample included a spread across treatment type, length of illness, education, employment and relationship status, although the majority of the sample was White British. Pre- and post-procedure patients were examined although the time-frame of the study did not allow individuals to be examined over time.

Pre-assessment clinics offer a valuable opportunity to identify patients at risk of distress and provide targeted interventions to improve illness coherence and treatment-specific knowledge in AF patients. In particular, information should be related to whether the procedure offers temporary or long-term alleviation of AF symptoms which may foster more realistic treatment expectations and aid alleviation of disappointment and distress in psAF patients. In order to provide targeted interventions, HCPs may benefit from education on appropriate advice for AF patients, which fosters adjustment rather than avoidance behaviours, or to help patients to have a more positive view of essential medication such as warfarin and other anticoagulants to improve adherence. Interventions focused on understanding distressing symptoms such as palpitations may reduce unnecessary hospitalisation and guided management of psAF symptoms could reduce unhelpful coping and lead to better feelings of control.

Conclusion

Many psAF patients experienced symptoms as distressing, unpredictable and uncontrollable despite behavioural attempts to cope, resulting in emotional distress. Low perceived knowledge exacerbated this vicious cycle which could continue even after successful treatment. Patients with better perceived knowledge reported better adjustment to having AF. Overall, concerns about treatment related to the efficacy of procedures, the likelihood of repeat interventions and the negative side effects of warfarin. Future longitudinal research should examine AF-specific illness and treatment representations and coping behaviours, and whether these predict QoL over time in different procedural groups.

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Appendices

Table 1: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Persistent atrial fibrillation.	Paroxysmal or permanent atrial fibrillation
Undergoing or undergone (within the past 3 months): cardioversion, catheter ablation or atrioventricular node ablation.	Severe comorbidities including: active cancer, end stage severe heart failure (NYHA Class IV), dementia/Alzheimer's, diabetes- and kidney-related hospital admission within the past year.
Over the age of 18.	
Ability to fluently speak and read English.	

Table 2: Interview schedule

Interview Questions	Prompts
General Questions	
Tell me about your experiences of living with AF.	How does AF affect everyday life?
Tell me about your experiences of treatment for AF	Have you had previous AF treatments?
Questions related to illness beliefs	
Can you describe your AF symptoms?	Which symptoms bother you most?
What do you believe are the causes of your AF?	What triggers your AF?
Questions about coping	
Tell me about other things you do, or have done, which help your symptoms.	Are there things which make your symptoms better or worse?
Questions about treatment	
How do you feel about the treatment you have received/will receive?	What were your expectations of treatment?
What is your understanding of the treatment you have received/will receive?	Do you feel that you have a good knowledge of treatment?
How necessary do you feel the treatment was/is?	
Did you have any concerns about the treatment?	Did you feel that there were any risks?

Table 3: Characteristics of the sample

Characteristics	Number (%)
Type of treatment:	
Direct Current (DC) Cardioversion	11 (37)
Catheter ablation	10 (33)
Atrioventricular (AV) node ablation	9 (30)
Treatment status:	
Pre-treatment	15 (50)
Post-treatment	15 (50)
Mean age:	61.6 (<i>S.D</i> =11.98)
Sex:	
Male	19 (63)
Female	11 (37)
Ethnicity:	
White-British/Irish/Scottish	29 (97)
Asian-British	1 (3)
Relationship status:	
Married/cohabitating	21 (70)
Other (Widowed/separated/single)	9 (30)
Educational level:	
Higher Education	16 (53)
A Levels/GCSE/O Level	14 (47)
Employment status:	
Full-time	14 (47)
Part-time	4 (13)

Retired	12 (40)
Comorbidities:	
Diabetes	5 (17)
Heart Failure	1 (3)
Kidney problems	1 (3)

Table 4: Additional examples of participants' verbatim illustrating each theme

Themes and sub-themes	Example quotations
Uncertainty and unpredictability of AF and symptoms	<p><i>"The heart is a strange thing but when it starts messing about you become very aware of your own mortality. And when it's beating very fast, there's a tendency for me to think myself, when's it going to suddenly stop just as quickly as it started?" (P27)</i></p> <p><i>"All of a sudden it was the same symptoms I had when I had the heart attack before so I knew something was wrong." (P20)</i></p> <p><i>"It's a frightening experience. It's like you have no control. The first time it happened I thought I was going to die." (P19)</i></p>
Behavioural coping	
<i>Avoidance</i>	<p><i>"Can't go for walks, swimming's out of the question, cycle, do my gardening. I used to take a children's church session every Sunday. Can't do that." (P29)</i></p> <p><i>"It's a case of believing them [advice from HCPs] and getting used to it." (P27)</i></p>

All-or-nothing behaviours

“I’m still trying to live my life as I would have done before because as I say, I’m social and I like going out but I find it very very hard and it’s such a hard time...you just try to cover up feeling really weird and a bit anxious and that makes things worse.” (P22)

“I was determined not to let it beat me...so I was trying to carry on as normal but as I said, getting tired very easily and not feeling like doing anything.” (P14)

Slowing down

“I used to try breathing exercises...but I pretty much try and find a quiet area to sit down.” (P10)

“Prevention has led me to meditation and to push back on them crazy working hours and trying to find stuff that’s good for the soul like reading and painting.” (P5)

“If it’s bad I’ve just got to sit and read and watch tele...wait for it to pick up again.” (P20)

“Obviously I’m taking it easy. I’m not doing cartwheels, I’m just trying to have a good quality of life, exercise, eat well so I can get

back to that.” (P18)

Concerns and expectations about treatment

Cardioversion

“The kind of stories I’d heard about warfarin. I hadn’t any experience of it but I was just kind of reluctant to want to take it.” (P14)

Catheter ablation

“It was a bit of a scary operation...the thought of going into hospital for two or three days, whereas the cardioversion was pretty short and sharp.” (P13)

“I’m trying to be positive about it, you know? I had two cardioversions and I thought that was going to fix it and it’s a bit disappointing you know, when it, when you come around and it hasn’t worked.” (P12).

Atrioventricular node ablation

“I am very anxious, I can’t do anything still. I expected things to be so much better afterwards.” (P21)

“I still have fast rates at times, so I don’t know if it has worked. I need to wait for the go-ahead.” (P29)

Figure 1: Diagram showing the overarching theme of a vicious cycle in everyday experiences of psAF patients. Low perceived knowledge exacerbates a vicious cycle of experiencing symptoms which are viewed as unpredictable, attempts to gain control of symptoms using behavioural coping strategies (avoidance, slowing down and all-or-nothing behaviours), appraising strategies as ineffective, and experiencing distress, which in turn exacerbates the experience of symptoms.

